

National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care in Acute Hospitals.

Please find below a response to the consultations questions about the national consensus statement from Kidney Health Australia. Kidney Health Australia is a not for profit organizations whose focus is to improve kidney health outcomes leading to substantial improvement to the quality of life for people with kidney and urinary tract diseases, their families and carers, as well as developing initiatives that reduce the incidence of kidney disease in the Australian community.

Kidney Health Australia recognise the importance of safe and high quality hospital care for those at the end-of-life. In 2007, one in ten deaths is related to chronic kidney disease¹.

Response to key consultation questions

1. Is the intended purpose and scope of the Consensus Statement clear? Why or why not?

Yes the purpose is clear.

2. Does the Consensus Statement accurately reflect what you think the expected standard of care and practice should be? Why or why not?

For psychological and spiritual care it is very detailed and very cognisant of the need patient centred care and shared decision making.

Comment: Section 3. Components of care; 3.10:

Whilst this section discussed the relief of symptoms it does not clearly articulate that the health professionals are responsible for regularly assessing for potential symptoms utilizing validated tools/pathways, that where appropriate are disease specific or all disease inclusive. In the reality of clinical practice many patients are not offered the opportunity to communicate all of their symptoms, and whilst the obvious symptoms of breathlessness or acute pain are more routinely addressed there may be less awareness by both health professionals and the patients that there are strategies to manage other symptoms. For example with end-stage kidney disease, pruritus, restless legs and generalized fluid overload are more likely to be present than pain. It is acknowledged that palliative care specialists are experts in this area, but health professionals in general acute environments including both medical and nursing may not be as experienced, and therefore structured guidance would ensure best-practice care.

Regular structured symptom assessment allows for appropriate referral to the specialist palliative care team. It also promotes a more comfortable end of life that encompasses the principles of good patient centred care.

¹ AIHW (2013). Chronic Kidney disease; the facts. Viewed at <http://www.aihw.gov.au/chronic-kidney-disease/>

As articulated in the consultation paper, effective communication is an essential requirement for safe and high-quality end-of-life care. This communication should routinely include the provision of information and seek the patient, family or carers views and wishes about organ and tissue donation for transplantation.

It should be standard practice for professionals to provide patients, their families and carers with information about organ and tissue donation so that they are given the opportunity to consider and make a decision about donation. This donation decision should be a routine part of end-of-life care that is the decision of the patient, their family or carer.

It is the responsibility of the health professional to ensure that factual information is provided so that patients, their families and carers are empowered to make a fully-informed and enduring decision.

Professionals need to be provided with the skills to compassionately communicate with patients, their families and carers during a difficult time in their lives, particularly when they have experienced acute and unexpected events leading to death.

Organ donation can only occur in certain circumstances when a patient dies in the Intensive Care Unit (and occasionally in the Emergency Department) after an acute and unexpected event. Tissue donation can occur in wider range of circumstances outside of the acute care hospitals and up to 24 hours after the patient dies.

3. Are the guiding principles clearly outlined? How do you think they could be applied in practice?

Yes they are clearly outlined. For implementation a national approach to determining the most effective and evidence based practice could be used to provide institutions with practical implementation strategies, systems and educational tools.

4. Are the essential elements clearly outlined? How do you think they could be applied in practice?

Yes they are clearly outlined. Institutions would need to ensure that their documentation reflected steps to ensure that all principles are met i.e. data systems that require answers to all pertinent questions to ensure that all aspects are clearly covered and that also inform care. Appropriate use of technology should ensure that data collection is not repetitive, is shareable and can be practically used.

5. Is there any terminology that needs further exploration or clarification?

No

6. What enablers exist to help with implementing the elements of the Consensus Statement? How can these be leveraged to promote best practice?

Educated and motivated health professionals are an enabler.

Comment – section 7; Education for health professionals. This section could include the need for educating health professionals in disease specific symptom assessment and evidence based management.

7. What barriers to implementing the elements of the Consensus Statement exist? How do you think these can be addressed?

The resources within institutions to develop and implement new policy may be limited or this area of practice may not be a high priority. National or state development of an implementation plan would best utilize resources.

In addition more national resources may need to be applied to ensuring advance care directives and personal electronic health records are integrated into everyday practice. To date, despite national campaigns both initiatives have fairly low rates of uptake. Research may also be needed to determine the causality of this.

8. In what ways can consumers engage with acute hospitals to help implement the elements of the Consensus Statement?

Hospitals need to invite local consumer representation on any committees or groups that are determining the related policies. Consumers can also be surveyed to determine gaps in current practice.

9. What principles and elements do you think need to be addressed most urgently in acute hospitals? Please list in order of priority (i.e. 1 = highest priority)

1. Changing the culture and improving education to increase the confidence of health professionals (not just palliative care specialists) in determining when end of life is approaching and acute active care is futile.

2. Acceptance of earlier discussions about the prognosis of diseases (other than cancer) and palliative care team involvement for chronic illness. This should prevent the sudden need for decision making to cease active treatments.

Kidney Health Australia would like to thank the Australian Commission on Safety and Quality in Health Care for the opportunity to respond to this document.

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